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PMLD LINK

The Bulletin of News and Information for Everyone Working with People with Profound and Multiple Learning Difficulties

CONTENTS

Report Back

PMLD LINK relies on contributions from practitioners, parents, carers and everyone interested in this field

EDITORIAL

Once again thank you to all the contributors to this issue of PMLD-Link, not only to those who found time to share their research, thoughts and practice in articles, but also to the reviewers who give us invaluable information about useful books and training materials and all those people who send us information about what is going on in the learning disabilities world which is of interest to readers working with and caring for people who have profound and multiple learning disabilities.

The theme of Health Issues has been explored from many different perspectives: the statutory obligations; the results of research; and, of course, practice in all kinds of settings. The issues raised will be recognised by all who are involved with people with PMLD whatever their role may be - we are all concerned with the health and wellbeing of those we work with and care for.

In this issue we have two letters/e-mails from parents asking for help - do please respond if you have any ideas which might be useful to them, and then send them on to me so that they can be shared more widely with other readers in a future issue.

Barry Carpenter, a founder member of PMLD-Link, and a continuing member of the editorial team, has written with information about the International Society on Early Intervention. This is just one example of his very wide ranging interests and the influence that Barry has in the whole field of learning disabilities for which he has been awarded an OBE in the New Years Honours. Congratulations to Professor Barry Carpenter OBE!

The theme for the next issue is Innovations in Practice, and in Future Focus Beverley Dawkins has started the ball rolling. Do write about your own practice, or encourage your colleagues to write in with any new ways of working that you have tried out and found effective, or tell us of any resources or equipment that you find particularly helpful - and don't forget to let us know about any ways you have found to get round the difficulties experienced by Irene Fergusson in managing incontinence, or any other aspect of personal care.

I hope that by the time that the next issue comes out we may have our own web site. *Watch this space!*

Business Matters

Thank you to all those readers who have resubscribed in spite of an increase in the cost. We do appreciate that the increase for organisations was quite lot, but we do want to keep the cost to a minimum for those people who pay for PMLD-Link out of their own pocket - and there are a great many of them! Thank you all for your loyalty.

Of course, PMLD-Link is only as good as you, the contributors, make it and all readers are potential contributors. Do write articles, do write letters, do ask for help, do tell us any news, do tell us if you have an active local group working on any particular aspect, do send in reports of any courses, conferences or events that you go to (particularly if they are useful).

Articles

Articles or any other material for the next issue should reach me by the 25th May. Please send them by post or e-mail (Rich Text Format please) to the following address:

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Good health is just a state of mind - or is it?

A general practitioner, known to the author, once stated that in his experience when his patients told him that they felt fit and healthy, they were generally psychotic or suffered a stroke shortly afterwards. He believed that we all have something that impinges on our health and well being which we are not 100% happy about.

Of course a large part of the time it is a minor irritation, yet for some people they live their entire lives with major health obstacles and disabilities. These people often have more than one disability to contend with. For the purposes of this paper I am referring to the small group of people who have profound and multiple learning disabilities or profound and complex needs and have tended to concentrate on an adult population. Throughout both papers the term 'carer' is used to denote any person be they a relative, professional, paid or unpaid who performs that role either in total or as part of their role. This is done to aid the readability, and attempt to redress the bias in favour of those whom this article is primarily about.

The article is in two parts - the first describes the politics around health care for people who have learning disabilities and some health promotion resources whilst the second will cover much more specific health problem areas.

PART I

"Budgets and all of that"

The health care picture for these individuals over the last decade has been patchy to say the least. To begin with there is poor clarification of how many people with learning disabilities in each local area there are nor are there any nationally (England) implemented criteria (DoH 1999). Whilst there are nationally agreed criteria, they are not consistently implemented. Local areas, services and professions often use their own criteria. For instance whilst the medical profession may use the DSM (American Psychiatric Association's *Diagnostic and Statistical Manul)* or ICD (*International Classification of Diseases)* measures this is not true of all services for people with learning disabilities. This will become more diverse now because the health services no longer occupy the key roles as service providers, meaning that other organisations are now implementing their own criteria; also with devolution the countries of the UK will inevitably move away from the English definitions.

This makes it difficult for services to budget effectively, and to receive the appropriate finance from central funds. Initially funding came from the government through the health boards. And since the funding was arrived at per population the revenue to large institutions was quite good in its day. However for individuals with learning disabilities living at home services were scant and poorly resources. Now most of the budget for people with learning disabilities is allocated by local government bodies through the boroughs and county councils, (apart from a much reduced budget for remaining specialist services for people who have learning disabilities still delivered through the NHS trusts). The budget is devolved through the various departments, but is set and dependent upon the council tax on home owners.

The vulnerability of funding revenues and services has recently been demonstrated when voters in the Bristol area last month (Feb. 2001) were asked to vote on proposed council tax increases (along with increased and improved services), for the council tax to remain the same, or to decrease the tax (which it was explained would mean a reduction in services - with a decrease in the number of teachers). The council said they would stand by the results of the vote. The voters of Bristol voted to reduce the council taxes and subsequent services.

However people in receipt of benefits are now able to apply to receive their benefits in full to spend as they will, rather than rely on the social service staff to commission the services on their behalf. This is a government initiative to empower people to make their own choices. But it has highlighted a number of anomalies in some areas. For instance, as the finance is transferred to individuals instead of services, some services are now charging higher rates for those on direct payments, than where services are 'block booked'

Health services in the past have been slow to unlock the funding for new service initiatives for people who have learning disabilities. This has meant that access to generic services has sometimes been barred. However with the introduction of the primary health care teams it is hoped this will cease to occur. This will mean that people who have learning disabilities and mental health problems, for example, will receive the services of the mental health services as and when necessary with greater speed and if also necessary specialist learning disabilities services in support. Hence there will be no separate service provider on the grounds that the person has learning disabilities alone, but this is not to say that there may still be the need for specialist services to support generic service providers and to research and disseminate best practices.

As Hutchinson (1998) demonstrates people with profound and complex needs often have unmet health needs because it may be seen as cruel or unnecessary to undertake some screening processes, there is a communication problem, carers may not be aware of a problem, or (and there are examples of GPs making this mistake also) it is seen as 'part of the learning disability'. People who have profound and complex needs are totally reliant on others, (often a small number of others) to access health services on their behalf.

Setting the political scene

In the early 1990s (DoH 1992) the Department of Health isolated a number of medical conditions in the general population which resulted in high usage of the NHS budget, for which, it was felt at the time, health education and early surveillance could play a larger part in helping people to remain 'healthier'. Also early detection and intervention could result in simpler treatment procedures and increased success stories, thereby also helping to minimize expenditure in these areas in the long run. Increased success rates for the health service would also be a politically desirable goal for the government of the day.

The health areas identified where improvements could be made were notably coronary heart disease and stroke, cancers, mental illness, accidents, HIV/ AIDS and sexual health. Public health campaigns, health checks and screening followed in an attempt to reduce the prevalence of these conditions and early intervention rates. However it soon became apparent that when certain groups of people were looked at, there were variations from the national picture, and three years later a strategy to improve the general health for people with learning disabilities was adopted (DoH 1995). This spelt out the rights of people with learning disabilities to receive the same services in health surveillance, care and promotion as the general public at large received.

Following on from this came greater guidance and clarification of role by the government in reiterating the implementations made in '*Signposts for Success*' (Lindsey 1998) which details examples of good practice and advice. It consists of three parts - for providers of health services for people with learning disabilities, a summary, and a health promotion game for use with people who have learning disabilities. This document forms the basis for the next report *'Once a Day'* (1999).

'Once a Day' is aimed at promoting good practice for people who have learning disabilities by primary health care team members. These teams are generally accessed through a local health centre or doctor's surgery. However as well as providing general information, there are examples of good practice, and two helpful lists at the end. One is of addresses of useful organizations, whilst the other is of publications designed for people with learning disabilities. This report is obtainable from the Department of Health, P0 Box 410, Wetherby LS23 7LN or it can be down loaded from HYPERLINK http://www.doh.uknhsexec/onceaday.htm

Initially it was assumed that people with learning disabilities had the same health problems as the general public; yet research showed this is not necessarily the full picture and the then new Learning disabilities Strategy listed nine health issue areas. These were orthopedic problems, respiratory problems, hearing and eyesight problems, mental illness, epilepsy, obesity and poor cardiovascular fitness, behavioral problems and communication problems (Harris, Bennett, Hogg & Moss 1997).

Health Information for people with Learning Disabilities

Health information resources for people who have profound and complex needs are scant, although the British Institute of Learning Disability (BILD) publishes a package of booklets for people who have learning disabilities on a range of health care subjects covering such areas as personal care, taking medicines, sexual matters, alcohol, smoking, diet, exercise, stress, seeing and hearing, and breathing easy (BILD1997). The package is beneficial for people who have learning disabilities some of the content may be adapted for use by carers for people who have profound learning disabilities.

The health promotion game which accompanies the *Signposts for Success* document is also in a format which may capture the interest and imagination of many, and form the basis of discussion, practical exercises or video information. This could also be presented in a context of workshops in small groups which could be sensitive enough, with adequate planning to take multiple learning routes to cater for a diversity of disabilities.

Over recent months more resources have become available in pamphlet and booklet formats for people who have learning disabilities.

The NHS Cancer Screening Programs produce two such leaflets entitled *'50 or over? Breast screening is for you'* and *'Having a smear test'*. Whilst these areas are also included in the 'Books and Beyond Words' series, (picture books designed for use by carers with those they support tel. 020 7235 2351 x146 price £10). Another entitled *'Good Practice in Breast and Cervical Screening for Women with Learning Disabilities'* is aimed at staff working in those screening services. Some of the above are available free of charge - more information from HYPERLINK mailto:nhs.screening@sheffield-ha.nhs.uk or HYPERLINK mailto:doh@prolog.uk.com.

Another organization called Women's Health is also producing a range of pamphlets for people who have learning disabilities covering areas such as thrush, hysterectomy, heavy bleeding and pre-menstral tension. The first is now available covering thrush. It is presented in picture format first, with drawings supplied by a lady who has learning disabilities and then repeated with accompanying words. Copies should be obtainable through the web site: www.womenshealthlondon.org.uk. Other health information leaflets are available from www.elfrida.com. Most of the material so far has tended to concentrate on health issues for women with little available to date for men.

It must be remembered that generally each NHS trust has a health education unit, as have most councils. These units contain a wealth of information covering many subjects. The information is often available with accompanying video and/or CD , slides, cassettes and aimed where applicable by gender/age. Information will also be available in different languages. Some health promotion units have mobile units which may contain interactive material - sometimes these can be found at local shows or travelling around schools.

Part II of this article will expand upon this section but will tend to look at examples of health promotion in relation to the specifics and local services and will be published in the next issue of PMLD-Link.

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Main Funding Sources - Learning Disabilities Services

Used to be the Health authorities - residential services in hospitals, hostels, small houses. Funding for community services was poor and aimed at fitting individuals into services rather than meeting individual needs. Over the last 30 years this has changed to be:-

Social services	Social care staff, occupational therapists, day services, social care, budget holder of residential services
Health authority	Speech and language therapists, school nurses, specialist nurses (LD), physiotherapists, occupational therapists, some specialist residential services, consultants, psychology, Department of Health education department
Primary Health Teams	General practitioners, health visitors, pracatice nurses, resource specialists and therapists, specialist nurses
Education	schools, teachers, support staff, portage teams, psychology, speech and language therapists, specialist teachers

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Parents' Placement Choices for Children with PMLD and a Medical Condition

Introduction

When we undertook our research in Scotland between 1995 and 1997 into the education of children with medical conditions, and when Alison subsequently edited a book on the same topic (Closs 2000), we included in our population, all children of compulsory school age affected by a medical condition, regardless of their abilities. There was a sharper focus on children attending mainstream schools, not because of the on-going inclusion debate, but rather because less was known about them, where they were and how their education in and out of school was being addressed, and about the responses of mainstream staff.

It was hard to define exactly what we meant by 'medical conditions'. We finally described seven broad groupings:

a) those who might, in conventional lay terminology, be considered a 'sick' or 'ill', sometimes to a life-threatening extent - as a result of genetic, infective or unknown causes, for example, children with cancers of various kinds, liver diseases, AIDS, acute rheumatic conditions, sickle cell anaemia, etc.

b) children with prolonged infective or viral conditions or responses to such conditions for whom a recovery may normally be expected at some unspecified time, such as tuberculosis, glandular fever, chronic fatigue syndrome (ME) etc.

c) those undergoing prolonged or recurrent surgery or treatment for orthopaedic conditions, serious injuries, organ repair or transplant, burns, etc.

d) children with genetically determined conditions which cause physical and/or cognitive deterioration and which are currently life-threatening/life shortening, such as cystic fibrosis, Duchenne muscular dystrophy, mucopolysaccharide conditions such as Hurler's syndrome, and Friedreich's ataxia, etc.

e) children who experience a range of symptoms or needs which arise from organ or central nervous system impairment, damage or other dysfunction, such as diabetes, epilepsy, heart conditions, kidney failure, etc.

f) children with otherwise more stable impairments who are subject to periods of associated illness, for example children with spina bifida who have recurrent urinary tract infections, children with cerebral palsy who have intermittent epilepsy, etc.

g) those with allergic or other responses to environmental or ingested substances, for example children with eczema and other skin conditions, asthma, bowel irritation, migraine, those who experience anaphylactic responses, etc.

(Closs 2000: 1-2)

Parents and teachers of children with PMLD will readily identify their children and young people in paragraphs a), d), e) and f). However, many children with PMLD may come within several of these and indeed also within the other groupings. While we avoided getting into unproductive arguments about 'whose needs were greatest', it seemed to us that the lives of families of children with PMLD and medical conditions were fraught with anxiety and that medical concerns could dominate many of the decisions they had to make, including educational placement.

Legislative and policy contexts

The right of children with PMLD to education under legislation enacted nearly thirty years ago, combined with the 'parental choice' legislation twenty years ago, means that the question 'Education - where?' looms large in parents' minds. This applies not only to the parents of children who have had

PMLD since birth, but also tragically to those whose children, while born appparently problem-free and who may have already entered mainstream school, are subsequently diagnosed with a deteriorating condition. Children and young people with PMLD generally have a Record of Need (Statement). The Education Authority (EA) will, as part of the recording process, have identified and named on the Record the school it considers a child should attend.

Parents who do not agree with the recommendation may request, as any parent may, that their child attend their choice of mainstream school within their 'home' EA. But parents of children with Records have additional placement request rights - at least in law - not extended to parents of non-recorded children. In Scotland the choices extend to any independent, grant-aided, self-governing or local authority special school. Parents may also make a request for any school in the UK or abroad that makes provision wholly or mainly for children with pronounced, specific or complex special educational needs. Children with 'significant absence' on the grounds of health have also the right since last year to education in hospital or at home. This all sounds almost too good to be true and, indeed, the reality of 'choice' is often extremely limited.

Placement requests are made to the EA in which children live but there are provisos in the 1980 Education (Scotland) Act, which allow the EA to refuse the request on any of the grounds of: availability of places, ability to provide suitable education for the child, effect of the child's placement on other pupils, and efficient use of the authority's resources. This last proviso may mean that the kind of provision that an authority already has may influence where a child is placed more than any consideration of what might truly be his/her 'ideal' placement. In Scotland the larger concentrations of population in the central belt and in the few larger cities allowed the building of special schools at the time when this was seen as the 'best' kind of provision for children with special needs.

Rural areas with more scattered populations were - and still are - more likely to include children with pronounced special needs within mainstream schools, often in units within the schools. This situation was exacerbated by the reorganisation of larger regions into more and smaller local authorities a few years ago, resulting in some authorities having no special schools while others had several or many. Most EAs, although advised by the Scottish Executive to develop co-operative policies, are intent on becoming self-sufficient in placements, often through adopting 'inclusive' policies which emphasise mainstreaming, and by developing small special support units within mainstream schools. Staff in these units are not always either very experienced or qualified.

Despite the widespread national emphasis on inclusion, and a legal requirement for mainstream education, under section 15 of the first Education Act passed by the new Scottish Parliament last year, the effects of the legal provisos and of parental choice mean that the great majority of children with PMLD - whether they have additional medical needs or not - are still placed either in special schools or in detached or semi-integrated special units and spend little or no time with peers who do not have special needs. An examination of what parents want for their children may cast further light on why this is currently so.

Parental views

What are the concerns of parents of children with medical conditions and do these apply equally to the parents of children with PMLD and medical conditions? We found that most parents had an explicit, or more commonly implicit, list of priorities (Closs and Burnett 1995).

- They wanted their children educated near home and to have some school contact with siblings and neighbourhood peers, even if some of their education was provided within a separate context.
- An individualised educational programme that recognised ability and potential as well as difficulties, and that was planned with families was important.
- Particularly high on the list for some families was the availability of medical and paramedical support as required, on-site, including properly planned and rehearsed emergency procedures where a child's condition required this. While parents recognised that school staff could not be medical experts, they needed to be sure that school staff were willing and able, once trained and legally indemnified, to carry out any necessary helping procedures and treatment. These could involve, for example, ensuring availability of oxygen, carrying out tubal feeding or medication, or applying rectal suppositories.

- Parents wanted their children to be safe, to be treated with respect by all staff and peers and free from any bullying or stigmatisation and they hoped that their children would find companionship and friendship.

Plainly, all of the priorities above also apply when parents of children with PMLD and a medical condition consider school placement. However, there were some additional issues (below) that emerged with these parents:

- They absolutely required both that their views and knowledge of their children be respected and incorporated in the school's planning and provision - home-school partnership had to be real and to be accorded the time it needed.
- They expressed concern too about the deployment of auxiliary staff in caring and facilitation roles. Would there always be adequate cover so that a child's school attendance did not depend on an individual auxiliary's attendance? At the same time, would there be enough continuity of auxiliary deployment that auxiliaries would be able to develop the deep knowledge of their child and sensitivity to little changes in his or her condition that would ensure their child's well-being?
- Would direct channels of communication about care between parents (or other home carers) and carers at school be established and respected, or would all communication be filtered through more senior educational personnel who might be less knowledgeable about care?
- Would the school also work in partnership with respite carers, if respite was established for children?
- Would the curriculum continue to be positive and developmental even if children's physical and cognitive conditions were deteriorating?
- Where children had extreme difficulty in communicating with other children (and vice versa), would schools facilitate companionship and friendship, including establishing 'circles of friendship' (Jupp 1992) where this seemed the best way forward?

It should be stressed that all of these concerns and priorities are entirely reasonable if equity of educational and social opportunity for children with PMLD and medical conditions is to be ensured. Special schools can provide many, but arguably not all, of the aspects of education and care that parents want. Meaningful contact with mainstream local peers is often problematic. The challenges to mainstream schools of including pupils with PMLD and medical conditions are, however, substantial and depending on attitudes of school and EA personnel, may be viewed positively or negatively. Some research indicates that teachers tend to overestimate the likelihood of medical crisis in their classes when pupils have medical conditions (Eiser and Town 1987). Ward et al (1994) found that teachers, asked to categorise the children they would most and least like to include in their schools, favoured least those who require physical/medical type care. Their inclusion certainly offers positive challenges for development of professional knowledge, skills and understanding. They offer peer pupils the chance to recognise and value human diversity. But they also require multiprofessional human resources, adequate facilities for access and treatment, cross-school staff development, extensive pre-planning and on-going extensive review of provision, sufficient flexibility to accommodate change as it occurs and excellent contact between key individuals at home, in the school, the education authority and child medical and social services.

Conclusion

As one clear-sighted parent considering where to place his child commented,"It boils down to shared knowledge and understanding, mutual trust and respect, the right people, lots of time, a fair bit of money and unending good will". This is not impossible and should be an entitlement, but where any aspect fails, the whole arrangement may collapse. There is currently a substantial element of pioneering when a child with PMLD is enrolled in a mainstream school. Such a venture, endorsed now in law, requires the on-going support of all and should not depend too much on parents - often the mother - and a hard-pressed head of SEN/Learning Support (SENCo) struggling on, while other essential partners from the EA, medical and social services only appear at times of crisis. Until such times as parents of children with PMLD and a medical condition can feel confident that all their children's needs will be met in mainstream, there is a likelihood that many will still opt, where they can, for the apparently greater security of a special school or larger unit placement.

Alison Closs and Claire Norris

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Professional Development Network
(Profound/Severe Learning Difficulties)

Professional Development Network is a group of people whose aims include support and collaboration to further cohesion in the organisation of accredited continued professional development for practitioners working with young people with profound and severe learning diffiuclties nationally and regionally. We also provide a forum for an open exchange of ideas including research to enhance professional development and understanding in the group.

Membership is open to anyone involved in providing accredited courses for practitioners working with young people with profound and severe learning difficulties. We meet twice a year at different settings around the country. We have a closed email discussion group.

Subscriptions are £10.00 p.a. to cover costs only.

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Physical Health Management for People with PMLD

We all of us need to look after ourselves. This includes everything from not walking in front of buses or tripping over furniture, to taking regular exercise and watching what we eat and drink. Of course we all know what sort of things are good for us and what are bad, although we do not always act appropriately, even with this knowledge.

It is therefore more difficult for those with a learning difficulty to manage their own health. Clearly there are certain aspects of a person's health that they may be capable of managing themselves and each individual should be assessed for the areas in which they may have competence. I feel that the main areas relating to a person's physical health which should be considered are: physical injury, diet (to include smoking and weight), personal hygiene, exercise and diagnosis of illness.

To take these various aspects in order, let us start with **physical injury**. Avoidance of this is, of course, to be our aim at all times. How can we achieve this? There are within PMLD such a wide variety of problem areas that it is difficult to know where to begin. I can best do so by citing examples of my own experience from our own care home. We have in the past cared for a wheelchair user who enjoyed some time exercising on the floor. It was necessary to carry out a risk assessment for this activity to ensure that he avoided, amongst other things, falling objects (including other residents) and careless feet. We also play host from time to time to a young woman who is visually impaired. Again through the vehicle of a risk assessment we have identified practices which help her and limit the threat of physical injury to her and others. This includes always ensuring that the respite room that she occupies is laid out exactly the same way every time that she visits and ensuring that she is always accompanied in the kitchen.

This leads nicely to a major risk area for physical injury within a domestic situation - the kitchen - the injury capital of any house. It sometimes seems as though every infernal device known to man lurks within the cupboards and drawers of the kitchen. Terrifying blades to slice and maim, poisonous substances, hot liquids and surfaces to burn you and a wealth of electrical equipment which may, at any moment decide to turn on you. The answer is risk assessment, locks on cupboards and drawers and proper supervision - here in the home and outdoors in the garden, or travelling out to the shops, or work and school. All activities should be properly risk assessed so that a person's safety and well-being is balanced with their right to choice and exposure to developmental experiences.

Next is **smoking , diet and weight**. Smoking is relatively simply dealt with. It is proven to be a most injurious habit to both the smoker and those around them and should be discouraged at every opportunity. If someone insists on smoking then perhaps persuade them to use lower strength cigarettes if possible.

We all know what foods are better for us than others and we all know what is a sensible weight. My experience of PMLD is that excess weight is a fairly widely found problem. Management of diet should be an effective tool in weight control as well as hopefully producing a healthy individual. Lower levels of fat and sugar intake are essential if weight is to be properly controlled and a healthy cardiovascular system promoted. It is always helpful to take advice from the dietician, just as it is wise not to be soft when being badgered for "just one more biscuit". It is my experience that a sweet tooth is common and a strong will on the part of carers is needed. You must be cruel to be kind.

Again, from our own care home experience (indeed my own family) the balance of a healthy diet for general health as well as weight control, with the occasional treat is not an easy one to keep. Medication can affect a person's weight and this can lead to extra difficulties. My own daughter Pauline, who herself has a severe learning difficulty, has added 10 kilos to her weight since being prescribed a particular medication. We were not told at the beginning that this was a known and fairly common side effect. It was only after our raising concerns with the doctor over her sudden weight increase, which we knew was not down to her eating habits, that this was made known to us. It is therefore important that one is vigilant for such things. A sudden increase in weight may be just as much a sign of a particular health problem as a sudden unintended loss of weight. Strength of will and vigilance on the part of carers are the watchwords when it comes to diet and weight.

Cleanliness is next to godliness, or so they say. Whatever your religious views it is important that we are all clean. Perhaps 'cleanliness is next to health' would be a better axiom. **Personal hygiene** on the part of carers as well as those for whom they care is essential for the good health of all. From top to toe: hair, nails, teeth, ears, eyes, nose, everywhere must be attended to. There can be no excuse for lack of hygiene, as poor hygiene will inevitably lead to health problems. It may be the dentist, or the doctor or some other healthcare professional, but eventually that is where a person will end up if they do not look after their personal hygiene. Make use of what is available. Make sure that regular visits to the dentist, optician, chiropodist are made and that carers act on the advice given. Keeping someone clean can, from my own experience seem like a full time job. But sores or other problems can rapidly develop if a high standard of cleanliness is not maintained, so in the long run it is far better to make the effort.

I know that it is not always possible for someone to go for a run, play tennis or football, but there are all sorts of things that can be done to effect some form of **physical exercise**. If someone is capable of walking, even if only for a short distance, it is important that they are given the opportunity to do so. This will provide much needed exercise and, if taken outside, expand their experience. Go to the park, or just walk a few paces around Tesco, it all helps. For those who cannot walk, the physiotherapist can provide an exercise regime suited to the particular needs of an individual. While the professional can formulate a programme of exercise they may not always be able to assist with carrying it out. It is therefore important that carers ensure that such exercise programmes are regularly undertaken if best health is to be promoted. It is, of course, important that all exercise, whether just going for walk or more structured programmes, is suitably risk assessed so that physical injury can be avoided. Regularly taken exercise can also help in controlling weight, but it is important to consider a person's weight and general level of fitness when deciding on what type and level of exercise someone is to undertake. Perhaps a visit to the doctor to establish what would be best for an individual should be considered.

This leads on to the final, and in some ways the most difficult and contentious area of health, certainly that we in our care home have to deal with. That is the **identification and diagnosis of illness** in people with a variety of learning difficulties. Our residents cover a wide range of ability. Some can make their aches and pains known to you clearly. For others it is more difficult. Our own daughter for instance is constantly bemoaning some ache or other and if we reacted to every single complaint we would spend half our lives in the doctor's waiting room. On the other hand, one of our residents has suffered a hernia for some time and it has only been through the vigilance of care staff that the fact was discovered. His very slow decline was barely noticeable and he is very adept at covering up any pain that he suffers. Even then it took a great deal of persuading to get him to the doctor at all. Once there, unfortunately the doctor himself was less than patient (no pun intended) and did not help matters.

It is possible that we are particularly unfortunate with our experience of the local GP to our care home. We have found that it is extremely difficult to persuade the doctor to take any input from the carer who accompanies the ill person to the surgery, when seeking to make his diagnosis. I understand that for the doctor it must be his decision and that if he gets it wrong it may rebound on him, but if his patient did not speak his language, he would presumably listen to an interpreter. This must be the role of the carer on a visit to the doctor when they accompany someone with a profound learning difficulty who has only limited communication ability. The doctor must be assisted in making his diagnosis by input from you. You almost certainly know his patient better than he does. Particularly if the problem is a new one for that person, the opinion of carers and their knowledge of the patient are important. Knowledge of the person, their moods and ways is an essential tool in monitoring their general health and identifying if they are in pain or discomfort. Maybe a headache or constipation is the problem, or could it be something more serious?

In closing I would say that, quite simply, when managing the health of someone with a learning difficulty, we should always seek to do so in the way that we know we should manage our own. We should not seek necessarily to apply the standards that we use for ourselves, but strive always for the best for them. Make use of other professionals, using their skills to help you make the best of someone's health. Do not be afraid to ask for help or advice from the physio- or occupational therapists. Talk to the dietician, district nurse and chiropodist. Consider alternative remedies such as aromatherapy, reflexology, homeopathy etc. Badger the doctor if you are not happy. You are, in most instances the voice of the person you are caring for. Stand up for them as you would for yourself and ensure the best health for them that you can.

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Healthcare for special needs children in a residential setting

The health and wellbeing of children with learning disabilities is of vital importance. In Autumn 1998 Sunfield residential school established a team of nurses to ensure that the health needs of the students were met. This article describes some of the developments of the Health Team since this time.

Historically, people with learning disabilities have much higher health needs than the general population for example, epilepsy, sensory impairments, behavioural phenotypes and vulnerability to mental health problems. Unfortunately, people with learning disabilities visit their doctor less frequently than the national average and use fewer preventative services. There is also evidence that many health problems are not identified by the person who suffers them, by their carers or by the primary health team. Children in residential care are also known to have poorer health and wellbeing.

Staff at Sunfield ensure that our students have the opportunites, support and help needed to lead a life which promotes mental health and wellbeing, including communication, relationship building, relaxation, healthy eating, stimulating days and personal achievement. Skilled staff are a scarce commodity, and the development of the Health Team has ensured that skills are deployed in the most effective way to support students and to train staff.

The Health Team consists of three nurses with a range of skills in children's, general, epilepsy, mental health, and learning disability nursing. Over the last two years we have worked to secure the best possible health outcomes for our students and to encourage a healthy life style.

Our first year was spent in ensuring that regular health checks were carried out, such as audiology, optometry, ophthalmology and orthoptic services needed to detect sensory impairments and to provide aids. Sensory disabilities and communication problems are often associated with challenging behaviour. Effective measures such as a second prescription for spectacles can ensure that a student prone to regular breakages can have access to a spare pair immediately.

Many syndromes and associated disabilities carry unique health risks; part of our role is to meet these needs in various ways, from arranging blood tests to monitoring development. This can lead to identification of previously unrecognised health problems that would otherwise impair performance, quality of life or longevity. Epilepsy is a significant hazard to health in the learning disability population due to higher death rate, injuries during seizures, greater risk of psychiatric illness, adverse effects of medication and the disruptive effects of seizures leading to under achievement, social stigma and reduced opportunities. The Health Team ensures reviews of all treatments and medication, and access to specialist care and consultants for the many children with epilepsy.

An important part of the Health Team's role has been to ensure safe practices, protocols and policies in regard to epilepsy and healthcare. Training of staff ensures equality of opportunity for our students.

During our second year a sick bay and clinical room with dispensary was developed. Specialist bathing and showering equipment has been provided and with doors widened, the area is accessible to all.

It has been important to establish a safe and calm environment which is cinical enough to meet professional needs but also friendly enough for our students. The surgery area is decorated yellow and blue (blue is associated with lowering blood pressure) and gives us an opportunity to develop an environment suitable for healthcare. We try to give time and make proper preparations for any procedure which can reduce anxiety, encourage co-operation and help develop coping skills. This then enables our students to access further healthcare support in more clinical environments with confidence for both staff and students. It can be as important for us to educate the medical staff we meet and undo the negative views we all come across at times.

Meeting our children's health needs can only be done in co-operation with all, particularly the families of our children. Working with the students, the staff, the families and each other has been an extremely rewarding and stimulating time and we hope to continue to provide a service that meets today's standards of healthcare.

> *"If you can get services right for people with learning disabilities then you can be sure that they will be OK for everyone else."*

Beth Grant
Care Manager (Health)
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Clent

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Developing better access to Primary Health Care Services for Adults with a Learning Disability

Introduction

Following the publication of '*Signposts for Success*' and subsequently '*Once a Day*' (NHS Executive, 1998; NHS Executive 1999) Adult learning disability services across the North West of England requested support from the North West Training and Development Team for a project to look at ways of improving access to primary health services for people with learning disabilities.

The NWTDT responded by appointing a part-time project worker to lead on this work. I have been in post since October 1999. This article is a description of progress to date. I would also encourage interested individuals to network with participants across the North West with a view to exchanging best practice.

Background Information

A wealth of evidence exists highlighting the fact that people with learning disabilities, despite having additional associated health needs, remain disadvantaged by poor access to primary health care services. (Allan, 1999; Rodgers, 1993; Turner, 1996)

A number of learning disability services across the Northwest region are beginning to take a pro-active approach to ensuring that Primary Care Groups and Trusts take account of the health needs of individuals with a learning disability by encouraging the establishment of surveillance and monitoring initiatives within GP practices.

The beginnings of partnership working between specialist adult learning disability services and primary health care teams also offers the potential to ensure that local implementation plans for the existing National Service Frameworks in Mental Health and Coronary Heart Disease take account of the needs of people with learning disabilities alongside the rest of the population.

Progress so far

In order to have the opportunity to make some input and connection to all adult learning disability health teams across the Northwest, cross-district networks were established that linked teams together building on existing relationships and geographical location. Each specialist learning disability team was contacted and asked to nominate a lead person to lead on the establishment of better access to primary health care in their particular district.

Five networks have been established over the past year, covering most of the Region as follows:

1. *Warrington, Halton, Wigan & Leigh and St Helens & Knowsley*
2. *Preston, Morecambe Bay, Lancaster & South Cumbria, Chorley & South Ribble, North Sefton & West Lancashire.*

3. *Manchester, Trafford, Salford, Stockport, Tameside & Glossop and Oldham.*
4. *Bury, Bolton, Burnley, Blackburn and Rochdale.*
5. *Cheshire and Wirral.*

Representatives from each district meet on a monthly basis for two hours. The purpose of the network meetings have been agreed as:

- *Sharing of information & best practice.*
  Each network meets on a monthly basis to exchange best practice, ideas, local and national developments, current literature, information and publications.

- *Networking.*
  Each learning disability team has agreed to contribute to the development of a Northwest directory of Learning Disability services and Lead Practitioners working to improve access to primary health care services with a view to making this information easily accessible to Primary Care Trusts in the near future via a publication from the NWTDT.

- *Development of sustainable care pathways*
  Participants have contributed to the development of a care pathway 'template' which is currently in its first written draft. It is our intention to use this work as a framework to assist individual districts to develop a local strategy and implementation plan. It is anticipated that this pathway work will be made available also via a publication from the NWTDT in 2001.

- *Problem solving*
  Participants are encouraged to actively engage primary health care colleagues with a view to strengthening partnership working and ensuring that the specific needs of people with learning disabilities are included in discussion about local implementation plans for the existing National Service Frameworks in Mental Health and Coronary Heart Disease.

- *Inclusion*
  Within the work to develop sustainable pathways, teams need to consider how to assist the developing Primary Care Groups and Trusts to establish forums for individuals and families that enable people to contribute to and influence the provision of health care locally.

Observations and lessons so far

We have a long way to go before we can truly make an impact, in measurable terms, on the health and well being of significant numbers of people with learning disability. However the development of Primary Care Trusts offers a chance for specialist learning disability workers and primary health care teams to work in partnership to develop a positive approach to surveillance and monitoring of health needs (Bollard and Jukes, 1999).

For this approach to be successful a number of prerequisite core conditions need to be in place, for example:

- *Sound strategic planning.*
- *Ownership of the initiative by key individual~*
- *A commitment to responding to some resource implications at a senior level and across agencies.*
- *A commitment to long-term partnership working between learning disability services and primary health care teams.*

Conclusion

These are a few of what have been identified as *'conditions that need to be in place to ensure that the right environment is created to nurture the growth of the initiative'*. The development of pathways and partnership working is not an accidental outcome; it requires substantial investment in terms of time, commitment and hard work at both strategic and operational levels and across agencies. However, there *is* a willingness to work and learn together across districts in the Northwest.

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Communication Passports
An effective communication aid for people who don't use speech

Although we were aware that there are few opportunities for non-speaking people with learning disabilities to guide and contribute to their health care assessment and service provision, we were surprised to witness the almost universal inappropriateness of the primary healthcare provision for this under-represented group of adults.

During a consultation with one optician's practice (notable for its willingness to examine and assess people with learning disabilities, in sharp contrast to most local optician's practices) we saw the optician base his assessment on questions about letters, numbers and colours. None of the people that he assessed in this way were able to answer. None of the responses given were able to inform an appropriate sight assessment.

It was the same story wherever we went. Primary health care practitioners, GPs, dentists, opticians or hospital staff team members, had little information about how to appropriately involve people with learning disabilities who do not use speech.

Partly because it is so crucial to elicit specific and *precise* nformation when it is a case of delivering primary health care, and party because of the time constraint, we found that all communication of health care assessment and treatment takes place between the support worker and primary healthcare worker. In most consultations the patient him or herself is left out of the essential conversation about their health needs, their diagnosis and their treatment.

Our idea was to create a body of information, a Communication Passport, that would enable people who did not know the individual well to feel confident in involving the non-speaking person in communication about their health needs. We felt that a quick reference resource could offer guidance that would ease relationship building between primary health care providers and their nonspeaking clients. The result of this information would be, we hoped, better communication and a window to more appropriate and effective health care provision.

After over a year spent working alongside individuals who do not use speech to communicate, we began to build a picture of each individual's communication style, their preferred environments and the kinds of things that worked well for them in terms of effective communication.

Each person is unique and so each Communication Passport has a different flavour from the next. However, every Passport comprises a VHS video and a small information booklet that reflects the content of the video. The Communication Passport is owned by the individual and may be used, with their consent, whenever and with whoever may find it useful.

The Communication Passport contains a 5 to 10 minute video showing how the person chooses to communicate the kind of communication they understand and how to support them to communicate with others most effectively. The Communication Passport also contains a booklet with the folowing information:

- Introduction to using the Communication Passport
- Contents
- Contact information and a picture of the person
- Information about how the person expresses themselves
- Information about how much spoken communication the person is able to understand

- Information on what you can do to support the person to understand what is being communicated
- A list of 'Golden Rules' - a short cut guide that enables you begin to communicate effectively with the person.

As a combined multi-media resource we hope that the Communication Passports offer a platform for building effective communication between primary health care providers and people who do not speak so that better, more person centred health care may be delivered. The possible use of Communication Passports goes far beyond the GP's and the dentist's surgeries. A team of care workers supported the people we worked with. They foresaw a range of uses for the Communication Passports including offering the Communication Passport information to new members of the support team, to daycare staff members and indeed to anyone else who needs to get to know the non speaking individual quickly and well.

There remain many questions:

? There are still issues of consent. How do we know that the person wants to share their Communication Passport information?

? All specific information about treatment, medication and indeed diagnosis continues to rely on the support worker knowing the individual well enough and then offering this information to the GP etc. Does good health care for non-speaking people rely on the quality of their paid support?

? How can primary health care providers offer a good service if there is no advocate to mediate and to model good practice?

Good health care provision for non-verbal people continues to rely on a sound values based response from professionals. With a person centred approach Communication Passports may promote independence, improve access to primary health care, reduce challenging behaviour, enhance respect and dignify and increase the capacity of all concerned to communicate effectively. But not without the right approach.

The Communication Passports offer no quick fix solutions to these issues but they do offer a chance to move forward and to build on the things we know work well for people who do not use speech.

As with all of us, being treated with respect, being welcomed and referred to throughout a consultation and being given a demonstration or explanation of what is being communicated is very useful. Communication is key.

Communication Passports offer an effective tool with which to navigate through what, for many people, is an unfamiliar landscape. By using the tools available to us we can grow in confidence in our own range of communications styles and begin to meaningfully include people who do not speak.

Duncan Yates 2001 **Patricia Finnegan**

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Don't Count Me Out

> *"[The person feeding Mary at school] had no experience, no training, no speech and therapy intervention, nothing."* Mary's mother.
>
> *"If only there was a nurse there to give medication and for other medical tasks [during school] I would sleep a lot easier at night."* Colin's mother.

Unfortunately, such comments are all too familiar to parents and carers of children with profound intellectual and multiple disabilities who are missing out on education because schools fail to meet their health needs. And it is an issue both in mainstream *and* special schools as the school nursing service has declined in some areas.

Colin and Mary's mothers' experiences are recounted in *Don't Count Me Out,* a new report published by Mencap. The report argues that children with health needs have the same right to education as other children – both in and out of the classroom, and on school trips.

However, research reveals a common failure of health and local education authorities to take responsibility for administering medication, such as oral tablets, rectal diazepam, nebulisers, oxygen and tube-feeding, during school hours should the need arise. As a result, children may have no choice of school, may be frequently absent or may be excluded from aspects of the curriculum.

In some schools there is no one prepared or trained to give medication to pupils. Some schools and local education authorities do not encourage teachers to take on these responsibilities. Also, there is a lack of clarity about which member of staff should take the lead in meeting the needs of pupils with health needs. Many parents rely on individual staff members taking on such a role on a voluntary basis.

Parents are overburdened

Mencap's study also found that some parents are expected to come to school on a regular basis to administer medication or help with feeding. This places an unreasonable strain on parents, particularly if they have to travel long distances, are employed or caring for other children. Many parents feel overburdened by having to be permanently on call.

Mencap believes that parents should not be expected to attend a school to help with their child's health needs. Instead, schools and the local education authority should be responsible for ensuring that sufficient staff receive specialist training in hands-on care so that an appropriate service is available at all times.

All too often, local education authorities and health authorities are failing to *work together* to meet the needs of individual pupils. Few pupils with health needs have a written health plan that sets out the responsibilities of each agency for the different elements of the child's care.

Recommendations for a new guidance

Don't Count Me Out recommends that the Government issues clear guidance with new responsibilities for health and education. This would mean that health authorities would be legally obliged to offer training and support to school staff and that school staff would have a duty to administer medication to children when – and if - they need it.

The report lists eleven detailed recommendations to the Government. They include the recommendation that funding should be allocated to allow Health Authorities to provide a prescribed level of training and support to school staff, to help them support children with health needs.

Three separate checklists for Health Authorities/Trusts, Local Education Authorities and school staff/governors are also enclosed in the report. These documents are designed to ensure that the agencies involved are doing everything that they can to ensure children with health needs can participate in school activities.

First-hand experiences
Don't Count Me Out is based on in-depth interviews with families, such as Gary's.

His mother, Wendy, said:

> *"We never knew how isolated Gary was until he went to this school. I'm not trying to be difficult, I'm not a difficult parent. I just want what is best for Gary."*

Gary, now 14, attended a special school for the first few years of his education, but his mother, Wendy, wanted him to experience a mainstream education at a local primary school.

When Gary started at the school in September 1997 – with the promise from the Local Education Authority that Gary's personal support assistant would be trained in administering rectal diazepam, the emergency medication that Gary might need if he had a prolonged epileptic fit.

September 1997 was also the date that his mother began her long battle for Gary's health needs to be met. Nearly a whole school year later, the promised training had still not taken place and by this time, the personal support assistant had decided that she was no longer prepared to administer the treatment.

The battle continued and, because of fears for Gary's health, Wendy took the difficult decision to withdraw Gary from school until the training had been held.

It was not until spring 2000 – nearly three years after he first joined – that trained staff were in place and Gary was able to resume his place at the school in his final year.

Further case studies from *Don't Count Me Out* include the following:

Mary, 7, has cerebral palsy and needs to be specialy fed or it could cause her death. Her family trained a classroom assisstant for three months, then went in every day for eight months to supervise. The assistant ended up moving to another class.

Colin, 14, has frequent, non-infectious, chest infections. He needs medicine from a nebuliser (a mask and oxygen chamber) to help him breathe. No one is trained to give him this low-risk, simple treatment, so Colin has to miss school.

David, 13 has a learning disability. He was excluded from a school trip in case he had an epileptic fit, until David's family complained. But the school then cancelled all future school trips for David's class.

Copies of **Don't Count Me Out** are available from Mencap's Public Liaison Unit Tel: 020 7696 5503/5593.

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SHARING IN SUCCESS
Communication Development at The Redway School

Introduction

The working partnership between a speech and language therapist and teachers described in this paper has grown over the last ten years. The development of the partnership has been possible by the determined effort of both professions to seek a satisfactory relationship that benefits the children we teach.

The relationship has been greatly enhanced by the provision from the school of a communication teacher who is not class based. This professional is a highly experienced class teacher and also has exceptional knowledge of communication. From the start her role formed a bridge between the two professions and then enabled a closer more practical working relationship.

The following section (boxed) which describes the challenges we faced, the resolution we have found, and the effect on staff and pupils forms the major part of a chapter in *Communication, Curriculum and Classroom Practice* (2001) published by David Fulton.

Challenges

As we look back to the early days there were three major challenges faced by both professions:

- differing models of service delivery
- differing knowledge of communication development
- time constraints.

Education

The role of the teacher is to deliver the curriculum to all pupils to ensure their educational entitlement. The teacher tends to focus on language that relates directly to the curriculum. For example the words describing mathematical ideas such as "bigger" or "smaller".

Teachers' knowledge of communication development is varied. Some may have little knowledge while others will have detailed knowledge of certain aspects eg linguistic development if involved with the *Derbyshire Language Scheme* programme (Knowles and Masidlover 1982), or knowledge of early interaction through work with pupils with profound learning disability.

Teachers have an obligation to deliver the National Curriculum. This leads to a full timetable leaving little time for essential learning requirements. It is worth noting that Q.C.A. (2000a) seems to have now addressed this issue to some extent.

Speech and language therapy

Speech and language therapists are both trained and managed by a medical model of service delivery. In this model the aim is to cure or find an acceptable resolution. A cycle of therapy is usually six to eight weeks it rarely lasts for the child's entire school career.

The speech therapist's job is to develop the child's communication through techniques based on normal child development. In normal child development the child will master language and communication through play and interaction with his environment. This is achieved before entering school to be taught the curriculum through the now understood medium of language. The knowledge of communication development held by the speech therapist is skilled but related to early child development.

Developing communication coherently through the curriculum is a new challenge. Therapists' knowledge of curriculum development is sparse. The need to understand all the curriculum areas daunting.

Speech and language therapists also have time constraints. Our research (Fraser et al 1998) showed that the allocation of speech and language therapy to pupils with severe learning difficulties is varied. At best it was shown to be one full time therapist for fifty pupils. Many schools had one therapist for 200 pupils. In these situations the therapist has to devise a working practice which meets the ongoing needs of all the pupils.

Use of the Framework

Looking at the challenges outlined above, it is not surprising that a resolution has taken years to find and not surprising that many therapists leave while the teachers are, as ever, left to struggle on!

The resolution we found is best summarised as follows:

- the shared framework for working
- shared responsibility for developing children's communication
- integrated working.

The framework is the essential starting point for sharing responsibility for children's communication development. This means both the speech and language therapist and teacher are responsible for developing a child's communication as outlined in the framework. The teacher's role is to focus and teach functional communication throughout the teaching day. The speech and language therapist's role is to support the teacher through assisting with planning the delivery of the curriculum, modelling good communication practice in the classroom and joint problem solving.

Sharing responsibility for communication leads to integrated working where recording, assessment, planning and teaching style are common to both professions.

The simplicity of the framework has enabled all to share the same understanding of communication and development. The division of the framework into just four bands enables teachers to group children by language and cognitive level for many subjects to ensure children can respond at an attainable but challenging level.

While detailed use of the framework does vary from teacher to teacher all use the broad banding system. This ensures a greater degree of consistent communication teaching and an effective place for the therapist as opposed to the all-too-familiar role as observer or helper.

Effect on pupils

The effect of the speech and language therapist and teacher working from the same framework is the development of a consistent approach to communication throughout the school.

The shared understanding promotes meaninglul discussion between staff of the complexities of children's communication difficulties. Sharing the same assessment enables all staff to see the progress as children develop through the bands or learn new skills within a band. Many staff feel more confident in their own communication with the children because they know where the child is and how communication works and develops. They can, rightly, take pride in the fact they have made a major contribution to the child's communication development.

This increased consistency, confidence and enjoyment of communication has enabled children to value their own communication attempts, to be more actively involved in curriculum activities and to know they will, for much of the time, be understood.

The development of communication is valued, not just as a vehicle for teaching the curriculum but as the core of the curriculum. For children with severe and profound learning difficulties this is crucial for their happiness and quality of life as well as their education.

COMMUNICATION AND COGNTION FRAMEWORK

BAND ONE - PRE-INTENTIONAL Developmental Language 0-5 months			
COMMUNICATION FUNCTIONS	METHOD OF COMMUNICATION	DEVELOPMENT OF THINKING SKILLS	SUCCESSFUL COMMUNICATION REQUIRES:-
Expresses: Likes Dislikes Wants Understanding of familiar and unfamiliar	The child expresses himself through: crying, stilling, smiling and vocalising.	Engages in sensory activities Relates to people or objects Explores objects by mouthing or banging Needs time to engage in non routine activities	An adult to respond to and interpret behaviours
BAND ONE - INTENTIONAL Developmental Language 5-9 months			
COMMUNICATION FUNCTIONS	METHOD OF COMMUNICATION	DEVELOPMENT OF THINKING SKILLS	SUCCESSFUL COMMUNICATION REQUIRES:
Expresses: Gains attention Requests Greets Gives information Responds by indicating yes or no Understanding is related to routines	The child expresses himself through vocalising, facial expression, pointing and gestures	People and object play is integrated Explores the function of objects Combines objects. Uses everyday objects in play	An adult to respond to the child's attempts to communicate and join in with turn taking activities
BAND TWO Developmental Language 9-18 months			
COMMUNICATION FUNCTIONS	METHOD OF COMMUNICATION	DEVELOPMENT OF THINKING SKILLS	SUCCESSFUL COMMUNICATION REQUIRES:-
Requests more, actions and help Asks for the names of objects and people Attempts to say names Indicates own belongings Indicates that things have gone or finished Indicates where things should go Describes qualities "YUK"	Expresses through a combination of methods such as gesture, vocalising and using objects, leading to using the formal system of signs and words	Learns through own activity Combines objects purposefully Simple pretend play e.g. with dolls Sorting in play	An adult to play, respond and comment on the game
BAND THREE Developmental Language 18-36 months			
COMMUNICATION FUNCTIONS	METHOD OF COMMUNICATION	DEVELOPMENT OF THINKING SKILLS	SUCCESSFUL COMMUNICATION REQUIRES:
Socialises Gives information Describes Directs Questions "who" "what" and "where" Repairs misunderstandings Understands and expresses in short sentences	Uses words, signs and symbols in short sentences and phrases e.g. "Daddy go work"	Sequences ideas in play Basic understanding of size, colour, number and position Needs to relate to here and now	An adult to clarify misunderstandings, answer questions and make communication fun and rewarding
BAND FOUR Developmental Language 3-5 years			
COMMUNICATION AND THINKING SKILLS	METHOD OF COMMUNICATION		SUCCESSFUL COMMUNICATION REQUIRES:-
Understands and expresses: Reasons and predictions Plans activities Negotiates Questions to find out information Understands abstract ideas and language out of context Early number and alphabet skills	Uses complex sentences containing joining words such as "and", "because"		An adult as an active listener to share ideas, clarify meanings and explain

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FUTURE FOCUS - Innovation in Practice

The theme for the next edition of PMLD-Link is 'Innovation in Practice'.

I recently attended the Choice Initiative conference where John O'Brien gave a presentation on the culture of choice for people with high support needs. He made the point that in his view "We sum up people as a diagnostic formulation e.g. 'people with severe learning disability, epilepsy and challenging behavior'. We pile up what they cannot do to justify the low investment that we make in the individual, the staff skills and the technology". He summarised this with a quotation from Norma Raynes (1980): "The less you've got the less you get". This, he felt, was an apt way to sum up the culture that people with high support needs live in. He said that in order to enable people with a learning disability to make real choices, we need to change how we are in relation to them, how we hear what they are saying and what we might do in response.

This is where the need for innovation comes in. There are some huge challenges to overcome in supporting people with profound and multiple learning disabilities which require us to be at our most creative, to challenge some of the traditional ways of doing things and find successful ways of changing services to better meet the needs of some of the most vulnerable people in our society.

The projects funded by The Choice Initiative at the Foundation for People with a Learning Disability are good examples of innovation in practice, and what can be achieved when we challenge assumptions. For example, it often seems that employment is not something that is regularly associated with people with PMLD. 'Step Out' was an employment project funded by the Choice Initiative. One project worker described how a man called Chris had collected quite a long string of diagnostic labels but was actually a 'biker'! He spent time getting to know Chris's interests and matched them to a job polishing motorbikes in a salesroom. Chris was given one to one support to do the job and over time developed skills doing something he really appeared to enjoy.

Housing is another area where some innovative work is going on. Whilst it is still true to say that if you have profound and multiple disabilities you are more likely to be living in a larger residential service and with a number of other people with PMLD, there has been some inspiring work going on by organisations such as Housing Options. They are able to demonstrate that having a home of your own when you have PMLD need not be the expensive choice that service providers often believe it to be and are able to give account of the benefits to an individual's quality of life when their individual housing needs are truly taken into account.

There are also the creative ideas and service changes that have flowed from Person Centered Planning (Sanderson et al 1997) and Circles of Support (Circles Network 1995). There was the young man described in *Unlocking the Future* (Kings Fund 2000) who wanted to climb a mountain and through his planning circle was supported in overcoming a number of potential barriers and fulfilling that aspiration.

These are all examples of innovation in practice. We would like to hear about some of the challenges that have caused you to re-think, have a go at something that at the outset may have seemed an unimaginable achievement. Have you got a story to tell about the way a circle of support has opened up a new opportunity for someone you work with? Have you participated in a project that has changed the way that you now work?

However, innovation doesn't have to be about big projects but about all those ideas you come up with, in response to everyday situations, that have had an impact on someone's quality of life. It is about the changes you have made in response to the daily challenges that you face. So whether you are a parent or carer, professional or voluntary worker, this is a great opportunity for you to tell us about all those good ideas you are sitting on and to let us in on the act!

Beverley Dawkins
National Officer for Profound Intellectual and Multiple Disabilities
Mencap

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report back .....

FORUM ON LEARNING DISABILITY
Seven Ages: Transition and Support in the Lives of People with Intellectual Disabilities

The conference was held on 7th December 2000 at the Royal Society of Medicine and was linked to the publication of *Transition and Change in the Lives of People with Intellectual Disabilities* edited by Dr. David May of the University of Dundee.

Dr. James Hogg chaired the morning session.

The meaning and significance of transitions in the life course of people with intellectual disabilities - Dr. David May, University of Dundee, Scotland, UK
Dr. May introduced his paper by giving an overview of the life course and the expectation we all have of changing attitudes, opportunities, experiences, complexity and variety of life settings. He commented on common attitudes to people with learning disabilities, and their ability to experience a normal life course.

Although there has been considerable progress in moving towards a normal lifestyle with more complex and varied opportunities through deinstitutionalization, community care and the embrace of normalization, research shows that the lives of people with learning disabilities still remain circumscribed and impoverished. They are excluded from roles most of us take for granted such as marriage and parenthood, employment, and retirement. There is often little variety in their lives from childhood to retirement

The pre-school and school years: Development towards adulthood
Professor Barry Carpenter, Sunfield School, Worcestershire, UK
Professor Carpenter introduced his paper by pointing out that preparing for adulthood is a legislated principle of the National Curriculum in England and Wales and this creates an enormous challenge to the curriculum and to the quality of teaching and learning necessary to achieve this goal.

He commented on the changing pattern of disability and some of the implications for learning:
- the increased survival of pre-term infants who may be 'devoid of emotional and sensory pathways which exist and co-exist, and which help to form the architecture of normal brain development' (Champion 1998);
- the increased importance of social causes such as drug and alcohol abuse, smoking, immunisation damage;
- increased sensitivity in the pain mechanism which may lead to emotional traumas. We must now consider the possibility that sensory approaches are less appropriate for some children.

He emphasised that the parents of a child with a developmental disability are frightened and confused, and that these emotions are never lost.

Clients and the parents are partners in the transition process throughout the various stages. He suggested a number of key principles for working successfully in teams including family focus, mutual value of team members, shared goals, collaborative work, evaluation of results.

Professor Carpenter proposed that early intervention has a number of primary goals. Those suggested by Wolfendale (2000) are:
- to support families in supporting their children's development;
- to promote children's development in key domains (cognitive, social, physical, emotional, linguistic) via early years curriculum and learning opportunities;
- to promote children's coping competence;
- to prevent the emergence of future problems.

Professor Carpenter also briefly touched upon the process of transition to early childhood education, transition through the school years and transition towards adulthood. He gave a resume of some of the current early childhood initiatives and new curriculum developments including the new Curriculum Guidelines for Children with Learning Difficulties expected to be available in Spring 2001.

The transition to adult life: from school to work?

Dr. Richard Byers, University of Cambridge School of Education, Cambridge, UK

Dr. Byers opened by referring to research which investigated the range of aspirations of school leavers with learning disability and he questioned whether the opportunities exist to match their aspirations. People with learning disability have a long tradition of working:
- in the home doing housework and care of family members;
- in long stay hospitals doing farmwork, gardening, domestic work, cleaning and cooking;
- in workshops in day centres and training centres doing light industrial work.

Low pay, or none at all, is usual and there are no prospects for promotion or career development.

He questioned 'Why work?' and suggested that it helps to ensure control over one's own life; choice; independence; the possibility of taking responsibility for others; finance for an active social life; improved self image, dignity and identity; and helps to shed the disabled status. It helps the person to acquire the indicators of normality including self esteem and being a contributor rather than a receiver - it confers adult status.

Dr. Byers then looked at the progression from the early models towards real jobs,
from segregation through a 'train then place' continuum. He described the supported employment model in the UK - competitive work in an integrated setting. The person is first placed, and then trained in the workplace with individual support.

The Association of Supported Employment Agencies is aiming at 'full participation' through a number of strategies providing different patterns of support, but he commented that barriers are created by the benefit system.

Finally he reported on the *Enhancing Quality of Life* research project.

An Adult Life in an Adult World

Professor Chris Conliffe, Institute of Counselling and Personal Development, Belfast, N Ireland

Professor Conliffe examined some of the implications of adulthood for people with learning disability, in an age when the lifespan in increasing for all. He emphasised the need for parity and honesty in the relationship between parents, a person with learning disability and professionals, and the need for a practical partnership between research and practice.

He suggested that there has been a change of pace with normalisation, social role valorisation, integration, inclusion, and self determination all contributing to improved practice.

He described four developmental life stages:

The First Age:	Early childhood, late childhood and adolescence
The Second Age:	Adulthood
The Third Age:	Late adulthood, well elderly
The Fourth Age:	Retirement, supported old age.

He noted that in northern Ireland school leavers (with an increasing number of pupils with PMLD) are emerging with raised expectations. He emphasised the notion of partnership - that when a child is born a social contract is created in the local community which is the basis of rights and entitlements.

The morning ended with Questions which covered the following topics:

Spiritual, moral, religious aspects of choice - Barry Carpenter commented that there is a clear thread in the social, moral, spiritual, cultural area of the curriculum which addressed informed decision making and judgement. Richard Byers said that the Quality of Life indicators exemplified spiritual development.

The Connexions Service - a replacement for the Careers Service (and other services) with pilot work to start in April 2001. The replacement of the Further Education Funding Council by Skills Councils and the freeing of the Schedule 2 restrictions. Transition planning is a major feature of the Revised Code of Practice.

Inclusion - the questioner asked if this government's interpretation was widening beyond mainstream schooling. An inclusive curriculum will be regardless of setting to protect from marginalisation. Richard Byers commented that inclusion is not just main streaming and suggested that total mainstreaming will not work. Special schools and specialist provision and staff will have a key role with specialist provision part of an inclusive move. Inclusion includes what they do at school and what support is needed to participate.

David May commented that the population is very diverse, and no one solution is going to right for all.

The afternoon session was chaired by Dr. May

Older families: transitions in later life

Professor Marsha Seltzer, University of Wisconsin, USA

Professor Seltzer examined the way in which parents' lives and well-being are affected by having a child with a disability. She referred to the Wisconsin Longitudinal Study which compared the family background, life course attainments of the parents, and the wellbeing of the family. Data was collected from three groups - parents with a child with a disability, either developmental or mental health and a normative group.

Although the situation is now more positive than in the past, the study showed that the three groups were similar at age 18 but their patterns of attainment and wellbeing diverged after that. Parents who had a child with a developmental disability had an altered pattern of attainment with lower rates of employment, larger families, and lower rates of social participation than the norm. However they were similar to parents who did not have a child with a disability in educational and marital status, physical health, and psychological well-being. In contrast, parents who had a child with a serious mental health problem had normative patterns of educational and occupational attainment and marriage, but elevated levels of physical symptoms, depression, and alcohol symptoms in midlife.

Professor Seltzer asked why do parents of children with developmental disability have no physical or mental symptoms? - and suggested that the answer may be adaptation early in life to the sacrifices such as mothers not working, and less socialising.

She pointed out the limitations of the study in that it was not qualitative, and therefore it lacks the richness of parents' stories.

A Parent's Perspective

Mrs. Rhona Lamond, Dundee, Scotland, UK

Mrs. Lamond gave a griping and moving account of the joys and the heartache involved in living with her son Craig who has profound intellectual disabilities. The recurring theme of *no place for Craig* led to a number of false starts and unhappy experiences, made more difficult by severe epilepsy and damaging epileptic drop attacks. The result of these experiences was suspicion and inhuman treatment and a number of changes of centres.

Finally, a centre was found where Craig is happy and the staff appreciate him. Family health problems led to the move towards a place in a custom built home shared with three other people with PMLD and all the worries involved in handing over care of a much loved member of the family to others. Initially there was a lack of attention to detail and understanding of Craig's likes and dislikes but happily Craig has now settled and "has the best of both worlds" having two homes and a secure future.

Mrs. Lamond described a life of managing, solving problems, harrowing stories, but over all - humour and love. She finished on an upbeat note saying that "Craig has given so much to the family".

Rights of Passage: Life course Transitions for Women with Intellectual Disabilities

Dr. Patricia Noonan Walsh, University College of Dublin, Ireland

Dr. Walsh started by referring to the EU Rights Model of service provision, and the World Health Organisation policies to promote healthy ageing among women.

She identified some key concerns around life course transitions:

- independence without risk - increased vulnerability of women with learning disability;
- marking adulthood - often not recognised through the usual school leaving rituals;
- living with families for longer than normal;
- limited workplace experience - lower income, shorter hours, stereotyped jobs, lack of value;
- bereavement and loss in middle adulthood;
- ageing in context - many older people whose carers cannot continue to manage are sent to unsuitable contexts, such as hospital.

Dr. Walsh then described the work of the International Group concerned with specific issues:

Reproductive health - there is lack of information, vulnerability, and other risk factors (comorbidity, medication, endocrine abnormalities, nutrition, physical activity, lifestyles) and psychiatric illness. Motor problems can create a barrier to good management and strategies may be used to manage fertility, e.g. sterilisation to control fertility.

Healthy ageing involves healthy behaviour and is affected by lack of personal social support. Women as consumers for health care can have an impact on employment and the training of health professionals.

From interviews with the women themselves it seemed that they had no concept of developmental age or the changes of ageing, and were reluctant to discuss sexual function etc. Age was identified with illness, professionals do not listen (time constraints) and procedures carried out may raise anxiety. Equipment was not accessible for those with physical disabilities.

Dying and Bereavement

Professor Sheila Hollins, St. George's Medical School, London

Professor Hollins introduced the subject by describing her experience as a psychiatrist in a long stay hospital. A man without speech was referred to her because of changed behaviour, and she diagnosed a bereavement reaction as his father had stopped visiting him because he had died.

She described normal grief which starts within one month, and the symptoms last for about six months. An atypical reaction may result in an adjustment disorder involving prolonged depressive reaction, mixed anxiety and depressive reaction; disturbance of conduct or a mixed disturbance of emotion and conduct. . People with learning disability are likely to have a longer adjustment disorder because of:

- the circumstances surrounding the loss, which may be sudden, violent, multiple and not anticipated because the person has not been told, or has been excluded;
- the characteristics of the individual, who may have low self esteem, previous failure to cope, suffer from separation anxiety or be unable to understand;
- the social support available, with other routines and relationships being disrupted, with other people making choices and decisions;
- the quality of the lost relationship, with difficulty in making new relationships.

Professor Hollins suggested a number of key points for caregivers including:

- listen, be there with the grieving person;
- be honest, include and involve them e.g. in the funeral;
- minimise the changes after any loss;
- avoid assessing skills until grief has been resolved;
- choose non-verbal rituals, such as music, mime or flowers.

People with learning disability may experience delayed, prolonged bereavement reactions. Professor Hollins described a project intended to identify ways of alleviating the symptoms.

A paper by Professor Hollins was sent to all who attended the Conference.

PIMD SEMINAR 27th February 2001
Curriculum

This seminar was originally due to be held in November but had to be cancelled due to the difficulties in making travel arrangements at that time. It was a very timely review by Dr. Christina Tilstone of the project which has produced the *Curriculum Guidelines for Pupils Attaining Significantly Below Age-related Expectations*, which is expected to be in schools by the end of March. A fuller report of the seminar will be published in the next issue of PMLD-Link (13.2).

Enhancing Quality of Life:

a project to develop transitional programmes for people
with profound and complex learning difficulties

Summary and Extracts from Newsletter 3: February 2001

The project continues to attract high levels of interest, positive comment and support. We now have over 300 names on the project mailing list; the newsletter is regularly published in *PMLD Link;* and copies are distributed at conferences and other events.

Members of the project team who work in the case study sites have written the following summaries to outline the project's priorities and the key objectives for the action research phase of the project at each case study site.

Barnet College and Creative Connections

Barnet College is a mainstream college of further education and Creative Connections is a project for people with learning difficulties run by The Institute, Hampstead Garden Suburb, an independent college for adult and continuing education. Both colleges make provision for adults with profound and complex learning difficulties.

The two colleges are commited to collaborating in the development of their innovative practice. Both offer part time courses necessitating links with residential homes in the private and public sector, resource centres and voluntary agencies.

We have identified key objectives for the research project, some common and some specific either to Barnet College or Creative Connections. In our common objectives we will be:

- comparing the arts therapy approaches used at Creative Connections and the use of Intensive Interaction at Barnet College;
- auditing and developing physical access for students with profound and complex learning difficulties within each college;
- exploring ways of collaborating between further educationand adult and continuing education colleges.

The provision at Barnet College is in its early stages of development and a key area of work will be to review and develop more appropriate assessment and recording systems. Secondary objectives will be to report back on the development of its curriculum for students with profound and complex learning difficulties and the assessment and development of students' communication skills.

Because the provision by Creative Connections is part-time its aim is to provide a holistic, integrated service, with students supported in courses by support workers, advocates or relatives who come from individuals' residential settings. Creative Connections will be delivering a staff training programme for these support workers. An audit of current practice in multidisciplinary practice and multi-agency work will be carried out with a view to documenting a framework for working holistically. A secondary objective is to involve service users in the research project, and to give examples of ways of promoting involvement and participation for people with profound and complex learning difficulties.

Bridge College

Bridge College is an independent day specialist further education college serving the needs of students with learning difficulties and/or physical disabilities in Greater Manchester and surrounding districts. Bridge is successful in creating an inclusive environment where young people are empowered to make the transition to adulthood by maximising independence and communication.

Approximately 25% of the 53 full time students (aged 16 to 22) have profound and complex learning difficulties. Providing an appropriate learning environment for this group of young adults has been a new venture. Members of Bridge's multi-disciplinary team continue to develop their skills in the areas of communication and independence (or aspects of planned dependency) for young people with profound and complex learning difficulties, and this work has been widely recognised.

In this project Bridge College is focusing on the use of multi-sensory environments (MSE's) and communication using objects of reference (OoR). We are hoping to produce two interactive multimedia CDs (a guide to good practice for the use of multisensory environments and a framework for the use of objects of reference) based around a central text with hyperlinks to other texts, pictures, and video with supporting documents. These materials will offer guidance on the development of best practice for students with profound and complex learning difficulties, addressing issues relating to inclusion and support for continued learning for adults across a range of environments.

The first objective for both topics has involved gathering materials, visits to other practitioners, contact with others renowned within the field and an audit of our current practice. Work has begun on composing central texts defining the topic areas, outlining progression routes and detailing implementation issues. We would be grateful to receive any information that would assist us in completing this task.

Oaklands College - the Springfield Unit

Oaklands College is one of the largest in the country with in excess of 34,000 student enrolments. Education and training is offered at four main campuses, three satellite campuses and a number of smaller sites. Springfield is based on the Oaklands Campus (one of the main campuses) and offers full range of full and part-time courses for young people and adults with learning difficulties and/or disabilities and gained the Tomlinson Beacon Award for Inclusive Learning relating to the provision for learners with profound and complex learning difficulties.

In this project staff will work with colleagues from other disciplines within the college and outside agencies to identify individual needs and learning outcomes more clearly, and to extend learning opportunities and progression routes for individual learners:

- to provide more effective transition routes both into the provision and when planning for future progression;
- to promote a more fully inclusive learning environment for both staff and students;
- to devise a pre-entry key skills framework to dovetail with our curriculum framework;
- to improve our tracking documentation and assessment of progress by all individuals involved with the learner and the learner themselves;
- to more clearly embed inclusive technology into the learning process.

Oldham Site

The Oldham site is made up of statutory and independent organisations operating in the borough of Oldham. Training into Employment (TiE) is a statutory organisation providing supported employment for people with disabilities. TiE has attracted funding to provide a range of services of which a transitions service for students in special educational provision is one. This focuses on students in their final year at school, and seeks to give practical support to students on work experience placements, and advice and guidance to parents/carers and schools.

New Liberties is a project providing inclusive leisure opportunities for people with learning diabilities using local environments with the view to facilitating natural friendships. The organisation became involved with the transition process in order to enable students leaving school to experience inclusive leisure opportunities of their choice. Aap Ka Haq works with students in transition from south Asian backgrounds providing culturally appropriate leisure and an important aspect of Aap Ka Haq's role is to help existing services to develop to meet people's needs.

In this project the Oldham site is focusing on interagency collaboration. We are hoping to produce a framework for agencies to work collaboratively (a guide to good practice) using case studies and text. We are also looking at advocacy; the process of change; and how we enable students with profound and complex learning difficulties to enter the adult world and experience employment and leisure opportunities of their choice. This will allow services in Oldham to reflect on their practice and produce a package based around text, case studies, video, symbols and photographs.

Our first objective has been to identify individual learners around whom we can build case studies. We have set up regular meetings to monitor progress and discuss issues relating to the transitional process. We are also visiting other practitioners in order to find information relevant to our projects and client group. We welcome information from other organisations undertaking similar projects.

Closing Comments

All of the project's case study sites would welcome contact with people who are working on similar or related issues. Please make contact with the project initially through the School of Education in Cambridge - details below.

Members of the EQoL project team will be consulting with managers and policy makers with regard to the strategic implications of the project and seeking the views of practitioners about the most useful form that the projects' outcomes take. We are planning a range of materials that will provide briefing notes for strategic decision-makers; practical guidance on setting up provision; academic papers in support of our theoretical framework and methodology; and an extensive pack to support the work of colleagues providing professional development for practitioners.

We have agreed that we will produce a traditional printed paper version of this pack. We are also keen to provide moving images, stills and electronic versions of the text. We would be very interested to have your views about which format will be most useful and accessible - standard video? CD Rom? and/or the web? Please send your response to Peggy Nunn at the e-mail address below.

Further information or comments to:
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letters ..... and ..... e-mails

from: **Irene Fergusson,**
78, Crabbs Cross Lane, Hunt End, Redditch, B97 5LG

I wonder if any of your readers (parents, carers or professionals) can help me find a solution to ongoing problems I have, finding some incontinence aids that meet the needs of my son, Gil? He is 38, has a profound learning disability and is dependent on others for all of his personal (and many other) needs.

Our local providers of incontinence resources offer a very limited range of aids that are neither effective nor comfortiable for Gil. He needs to wear inco pads at night, with a waterproof draw sheet on his bed underneath. Our present pads do not contain the moisture, resulting in wet beds daily and lots of washing for me! Part of the problem is Gil's shape. His 'middle-age-spread' means the pad has to be fastened above or below his paunch making it difficult to get a seal, which then allows moisture to escape. In the past, his respite carers have tried putting an extra slip pad inside. This is more waterproof, but appears uncomfortable and makes him very sore.

Until recently, we were provided with disposable, waterproof bedsheets. More recently, we have been given some washable draw sheets to replace the disposable ones. These work reasonably well, but are difficult to wash (very specific washing instructions) and the materials make them very slow to dry.

Our local services offer us only one range of pads in different sizes. We are also given a strict 'quota' of inconcinence materials, based on their assessment of Gil's needs. On months when we need more, these are simply deducted from next month's quota! I realise this is in part due to budgets and cutbacks, but feel there must be an easier way to meet Gil's (and my) needs.

I'm sure I am not alone in this problem. Other parents, in my area, have expressed similar concerns at our local support group meetings. My hope is that some one knows of something that might work better than what we have at present - to make Gil's life more comfortable and mine less hard work!

Anny suggestions appreciated, and will be shared with other carers in my area.

Yours hopefully ....

Can you help Irene?
If so, contact her at the address above and share your ideas with other readers too by sending on the information for us to publish in a future issue

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from: **Elena dal Bo in Argentina**
ecobenia@netverk.com.ar

I am having a great task these days as, with Juan's special teachers, we are trying to have him integrated into a mainstream school. The mainstream school agrees to take part in this plan, but we are having a struggle with the education authorities. The inspectors are the hardest to deal with. Juan is considered to be 'unintegratable' and, although we say that no matter how disabled a child is, he deserves to be in an ordinary environment, they keep asking about expectations of achievement, and things like this.

I would like to ask you which arguments about assessment of achievements, and about the achievements of children with SLD compared to their non-disabled peers in a mainstream school, you would use to support our position. ...Perhaps you could give some examples?

If you have any suggestions for Elena e-mail her with your ideas

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from: **Professor Barry Carpenter**
Sunfield School, Clent, Stourbridge, Worcs DY9 9BP

"I have recently been elected to represent Europe on the World Council of ISEI, and would like to promote the work of the Society more in the UK and Europe.

The information offered by the Society through its web-site, bulleting boards and e-mail facilities is excellent. There is a very great need to promote Early Intervention in the UK: it does not have the kind of profile or status in this country that it enjoys in Europe and the States. Many British professionals working in the field of Early Intervention can often feel isolated, and contact with, and through, other ISEI members may be one way of reducing this.

Dr. Michael Guralnick, President of the Society, is about to begin a major research project on Early Intervention and Children with Autism which may be of interest. Hopefully the Society's next International Conference will be in Rome in 2002."

He has sent the following information about the society:

INTERNATIONAL SOCIETY ON EARLY INTERVENTION

Providing effective early intervention programs for vulnerable children and their families constitutes one of the most important challenges for contemporary societies. State-of-the-art intervention requires the contributions of specialists from many disciplines, the construction of programs that are firmly rooted in biomedical and behavioral research, a program development component that is capable of incorporating emerging research findings, and advocates and administrators to ensure that funding, personnel, and related resources and policies are available and consistent with the knowledge base and goals of early intervention.

The rapidly expanding numbers of children worldwide who are at-risk for developmental and health problems due, for example, to poverty, prematurity/low birthweight, infectious diseases, or to exposure to toxic substances prenatally or during early childhood demand a supportive and effective set of well-designed services. Often co-occurring threats to development that are the result of abuse or neglect or parenting practices compromised by mental illness or limited abilities of caregivers are reaching epidemic proportions in many countries. For all risk populations, early intervention is best conceptualized as providing preventive intervention, i.e., efforts to prevent or minimize the impact of risk factors on a child's development and general well-being.

In addition to children at risk, children and families with established disabilities have historically been of central concern to the field of early intervention. Included here are children with intellectual disabilities, autism and related pervasive developmental disorders, motor disabilities, communication and language problems, behavior disorders, and hearing and visual impairments. The value of effective early intervention services for children with established disabilities and their families cannot be overestimated. Even if children fit easily into one of these categorical groupings, providing comprehensive, supportive, and effective service requires a remarkably high level of sophistication and understanding of developmental processes.

Purpose of the Society

Issues relevant to early intervention transcend national boundaries. The rapidly expanding knowledge base of early intervention is the product of contributions from researchers, clinicians, program developers, and policy-makers from numerous countries. Communication within and across national boundaries of these advances has improved in recent years due to technological innovations, greater availability of journals and reports, as well as increased interest in international organizations. Yet international early intervention collaborations and sharing of knowledge are far from adequate. In part, this state-of-affairs reflects continued difficulties related to communication between specialists representing numerous disciplines, communication between basic and applied scientists, and communication between researchers and those concerned with the practical implementation of programs. Moreover, the tendency of international organizations to focus on a specific group of children, such as individuals with established intellectual disabilities or children at risk for developmental problems due to prenatal exposure to alcohol, does not easily permit early interventionists to address the critical issues that transcend disability or risk status.

In view of this, the primary purpose of the ISEI is to provide a framework and forum for professionals from around the world to communicate about advances in the field of early intervention. The membership of ISEI is composed of basic and clinical researchers relevant to the field of early intervention representing a diverse array of biomedical and behavioral disciplines, as well as clinicians and policy-makers in leadership positions. As such, linkages between basic science and applied research, interdisciplinary collaborations, and connections between research and practice will be emphasized. To foster communication and research collaborations, the ISFI will sponsor or co-sponsor international conferences, provide information about conferences relevant to the field of early intervention, publish a membership directory, and establish an information exchange mechanism through the Internet. From time-to-time, the ISFI will publish monographs or books of special interest to its members.

Organisation

The ISFI membership is organized on a country-by-country basis. Although membership is individual, this structure is designed to take advantage of existing within-country networks and to complement established professional activities and organizations. At the present time, it is not anticipated that dues will be required. Access to the internet will be the responsibility of each member.

About The Web Site

Our ISFI Web site is located at the Center on Human Development and Disability at the University of Washington in Seattle, Washington, U.S.A. The site will continue to grow and evolve. Please send any comments or questions to isei@u.washington.edu.

For further information, please contact;

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POETRY FOR ALL

Following the success of *'Reading for All'*, Mencap City Foundation are funding the development of a resource dedicated to the use of poetry across the range of ability. *'Reading for All'* contains material for people of all ages - from material for very young children to the heady delights of dramatising the French Revolution! It is hoped that Poetry for All will also be a useful resource for people of all ages.

So if you have used poetry successfully, or know someone who has, please send any material (by post or e-mail) that you would like to share with colleagues to the address below by June 30th 2001. We would be particularly interested in receiving material that reflects an ethnic and cultural diversity that wuld help to make the book, literally, Poetry for All.

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news ... news ... news

Award for Southampton Teachers

Two teachers at the Mourdant School, run by the Rose Road Association, were awareded the pretigious fifth Fulton Fellowship Award in Special Education which has enabled them to put their skill and knowledge together and produce a book.

The book, titled ***Baseline Assessment, Curriculum and Target Setting for Pupils with Profound and Multiple Learning Difficlties*** is concerned with the assessment of pupils with profound and multiple learning difficulties and will act as a comprehensive guide to help teachers and other professionals involved in the assessment and target setting for pupils with very complex learning difficulties.

This is a wonderful achievement for Sonia Maskell and Fran Watkins who have worked hard to put the book together alongside the daily demands of their teaching jobs. The book is based on the work developed over the last six years by specialists at Mourdant School in partnership with a range of professinals, consultants and experienced teachers of children with special educational needs.

Sonia Maskell has a background in Early Years Teaching and for the last fifteen years has worked with children of all ages who have very complex needs.

Fran Watkins came into special education twelve years ago after many years spent in mainstream settings. She has mainly been involved in working with KS4 and post 16 pupils with profound and multiple learning difficulties.

The Mourdant School in Southampton is an independent special school run by the Rose Road Association and supported by Southampton City Council and Hampshire County Council. The Rose Road Association currently provides education, care and respite.

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handseltrust

Research demonstrates parents lack support thoughout the UK

The Handsel Trust has published the results of a UK postal survey which asked 500 parents of children with disabilities for their views on support available to them as parents.

"I met an incredible amount of professionals but, as a mother, I felt very isolated."

The above quote is typical of the responses received from parents throughout the UK. Over 40% of the parents felt that there was no attempt to find out what their needs were during the first weeks after they became aware of their child's disabilities.

Parents said that they needed someone to talk to, someone who knew about disability and the services and benefits available and someone who could co-ordinate all the people working with their child. Respondents came up with many reasons why support from other parents, while very useful, is not an adequate solution on its own.

Parents came up with a comprehensive list of recommendations on how they wanted to be treated for example, workers being knowledgeable and positive and respecting their expertise as parents. The research demonstrated that too few parents experience such input. Where individual workers were found to be supportive, parents felt this was more to do with their own motivation and personalities rather than their job descriptions.

Peter Limbrick, the chair of the Handsel Trust sid "*The research is an excellent resource - parents talk of* *practical and realistic ways in which we can better support them. The report is a positive way forward from the lack of support which affects parents throughout the UK."*

The results of the research have been pulished in plain English, non-jargon form as ***Parents' Support Needs*** available for £6.00 from the Handsel Trust.

For a copy of the report, please send a cheque for PO for £6 to The Handsel Trust, 83 Silver Street, Kings Heath, Birmingham B14 7QT. For a complete list of Handsel Trust publications, please call 0121 441 1580.

The Foundation for People with Learning Disabilities Publication of new Report

The Foundation for People with Learning Disabilities, part of the Mental Health Foundation, has bublished a new 56-page report, *Learning Disabilities - the Fundamental Facts.* The research report brings together all of the available key facts and figures on the prevalence of learning disabilties, additional and unmet needs and service provision, including costs.

Learning Disabilities - The Fundamental Facts, which was funded by The Shirley Foundation, also highlights the lack of information available at a national level. For example, with no reliable official statistics, the number of people with learning disabilities is estimated at anything between 810,000 and 2,100,000 - a considerable difference for anybody planning national services.

Learning Disabilities - the Fundamental Facts is available, price £22.50 plus p&p from the Mental Health Foundation, 20.21 Cornwall Terrace, London NW1 4QL or Tel: 020 7535 7441.

Planning, teaching and assessing the curriculum for pupils with learning difficulties

Curriculum guidelines for pupils achieving significantly below age-related expectations have been developed on behalf of QCA. Two sets of these materials will be distributed to special schools, schools with special units and local education/unitary authorities in the week March 19 - 23. Other schools with pupils with learning difficulties will receive one set via their education authorities. The materials will also be found on the National Curriculum inclusion website at HYPERLINK http://www.nc.uk.net from the beginning of April.

The non-statutory guidelines are for pupils between 5 and 16 who are not expected to achieve beyond level 2 at key stage 4. These pupils are often described as having severe, profound and multiple or moderate learning difficulties. The guidelines are applicable to mainstream and special primary and secondary schools, special units and independent schools. They have been developed to support not only teachers and other staff but also the range of services that work with these pupils.

The guidelines contain:

- a booklet on planning, teaching and assessing the curriculum;
- a booklet on developing skills across the curriculum;
- booklets on planning, teaching and assessing each National Curriculum subject, religious education, personal, social and health education and citizenship.

The guidelines have been developed by a team from the universities of Birmingham, Cambridge and Cardiff, together with representatives from EQUALS. The core development team has worked with subject specialists from QCA, acknowledged experts, practitioners, the Department for Education and Employment and Ofsted to build on the innovative curriculum development and practice in schools throughout the country.

reviews ... *reviews* ... reviews ... *reviews*

Choice Discovered – A Training Resource
The Foundation for Learning Disability
Tel: 020 7535 7441

This training resource comprises a video and handbook produced by The Foundation for People with Learning Disabilities. It provides a template for the training of staff working directly with people with learning disabilities in aspects of communication and choice making.

The video provides insight into the experiences of five people with learning disabilities and their support staff. It is well presented and demonstrates the kind of activities that people with learning disabilities can be involved in, regardless of the level of that learning disability. The staff interviewed gave realistic comments about their experiences and their hopes.

The handbook provides all the necessary material for a single day training session or three shorter training sessions. It sections the material off into Methods of Communication; Someone to Communicate with; Something to Communicate. Each section is then subdivided into aspects of that area, with an aim, introduction, exercises to do, discussion points and an outcome.

The teaching approach is very easy to follow and focuses on the basic requirements that those working directly with people with learning disability need to know. All the exercises relate to people with learning disabilities, which creates the direct relation of theory to practice.

The title of the pack is somewhat misleading in that the content is heavily weighted to communication generally. It would have been helpful to have covered in more detail aspects of work around choice making, such as how to begin helping people learn how to make choices and what kinds of things to focus on. Issues such as information being presented in a concrete or abstract form and consideration about choices needing to have purpose, were passed over but are important to engaging and motivating people.

As part of the introduction to the training it would have been advantageous to remind participants of the reasons for giving people choices, with references to values and rights. This may be considered to be fundamental however it is important to remind participants at any opportunity as to the reasons for them being there.

Choice is an area that is important to all people, something that paid staff and carers can sometimes struggle with particularly when the person has a profound learning disability. The exercises provide some good exploration of personal stance and beliefs, however the discussion points highlighted within the text could have had more emphasis placed upon them. Whilst the pack provides a template, it would not be sufficient for someone to use without prior knowledge and experience of this area of work. Trainers would have to draw on their own experiences to add to the content and be able to provide some insight into issues that participants may raise. Some services, which have already developed training in these areas, may find the training material basic, but will not find another video to match! All in all a good resource for any service involved with people with learning disabilities, which would be easily adapted for use with people with learning disabilities, their parents and carers.

Christine Hutchinson
Community Nurse Learning Disability
North West

Approaches to Teaching and Learning (Including Pupils with Learning Difficulties)
Written by Ron Babbage, Richard Byers and Helen Redding in association with St. John's School, Kempston
Fulton Press 1999 ISBN 1-85346-575-5 pp.106

Approaches to Teaching and Learning consists of a Foreword and five Chapters which cover the purpose and intended audience for the book, definitions, descriptions, developments, conclusions and implications.

The authors used the award of the Fulton Fellowship 1998/99 to initiate and implement an inquiry into teaching and learning and inclusive practices; the resulting discourse and analysis is represented by the following chapters. Inclusive ideology both within segregated and non-segregated settings is central to the thinking within these chapters and what is proposed is a direct link between success or otherwise largely depending upon effective pedagogy.

Chapter one 'Introduction' deals with Schon's (1991) model of the 'reflective practitioner' including action research as a tool for understanding organisational change, schools and their context with suggestions about how this book could be used.

Chapter two 'Definitions' deals with the culture of organisations, how change impacts and gives suggestions about the nature of successful change. The nature of successful change is linked with a 'learning culture'. There is a substantial discourse exploring teaching and learning definitions leading into an explanation of where society is today in terms of inclusion. This chapter also includes some discussion about the role of the special school and the specialist teacher.

Chapter three 'Descriptions' intelligently provides an overview of changes in special schools that have taken place within methodology since the late 1980's, including National Curriculum and Ofsted and their impact upon professional judgement. The next sections analyse processes and skills involved in various teaching and learning settings.

Chapter four 'Developments' explores learning preferences and profiles leading into 'engagement in the learning process' and discusses the idea of 'learning to learn' a move from passive recipient to engaged learner.

Chapter Five concludes the book, picking out generalisations and the importance of cross phase and sector collaboration and the need to continue the development of successful pedagogies.

This is a well written, intelligent and thought provoking book and I recommend it to you although I would suggest that it is slightly more specialist than it purports to be. Anyone new to the field, would find the Reference section a useful guide for further reading.

Steve Morris
Head Teacher, Grimsbury Park School, Bristol.

Transition and Change in the Lives of People with Intellectual Disabilities
Edited by David May (2001)
Research Highlights in Social Work: Jessica Kingsley Publications

This volume tracks and critiques research around transitions that happen during the course of peoples' lives, from early to later years, and engages with the experience of people who have learning difficulties/disabilities and their families. It focuses particularly on the impact of community care policies during the 10 years following the publication of *Living with Mental Handicap: Transitions in the lives of People with Mental Handicaps* edited by May and Horobin (1988), in which the editors introduced the concept of the life stage. The NHS Community Care Act (1990) is taken as a turning point in the evolution of community care policies and official attitudes towards inclusion.

The book reflects positive developments that have taken place during the intervening decade as the balance of care shifted from institutions to community settings, although much of the progress reported has been made by those whose disabilities are less severe. Chapters concerning opportunities for people with learning difficulties/disabilities to marry and have children would have been unthinkable just a decade ago, but these developments, alongside improved access to further education, independent living and supported employment continue to be denied to those who have higher support needs. Most of the examples in this book concern the more able among the cohort.

The editors are careful to include the views of carers, reporting on the changing nature of the support that is needed and provided by carers during the early years, adolescence and later years, and also provide an interesting perspective on way in which the experience of disability is mediated by gender, health and age.

Despite the very real progress that is reported in this volume, contributors continue to voice questions about the downside of dispersal of individuals into the community and to recommend ways in which society can shift "in acknowledgement of the fact that there are many varieties of a 'normal' life, all equally valid".

In all, this book provides a useful contribution to the field. It would be interesting to review some of the more recent post-school developments, for example in education and in supported employment, in the light of this analysis.

Helen Hayhoe
School of Education
University of Cambridge

NEW BOOKS

Planning, Teaching and Assessing the Curriculum for Pupils with Learning Difficulties published by QCA

Baseline Assessment, Curriculum and Target Setting for PUpils with Profound and Multiple Learning Difficulties by Sonia Maskell and Fran Watkins published by David Fulton (2001).

A Sensory Approach to the Curriculum by Judy Davis, published by David Fulton (2001)

Parents' Support Needs : The views of parents of children with complex needs by Gudrun Limbrick-Spencer, published by The Handsel Trust, 83 Silver Street, Kings Heath, Birmingham B14 7QT

Communication, Curriculum and Classroom Practice by Clare Latham and Ann Miles, published by David Fulton (2001)

Caring for Kathleen: A Sister's Story by Margaret Fray, published by British Institute of Learning Disability (2000)

Transition and Change in the Lives of People with Intellectual Disabilities edited by David May, published by Jessica Kingsley (2000)

Sensory Drama for Very Special People by Flo Longhorn, published by Catalyst Education Resources (2000)

A Framework for Learning by Caroline Allen, published by David Fulton (2001)

Towards a Curriculum for All: a Practical Guide for Developing an Inclusive Curriculum for Pupils Attaining Significantly Below Age-Related Expectations written by the Dorchester Curriculum Group, published by David Fulton (in press)

Don't Count Me Out - a Report published by Mencap (in press).

Parents' Support Needs a Report produced by The Handsel Trust Tel: 0121 441 1580

Learning Disabilities - The Fundamental Facts a Report produced by the Mental Health Foundation Tel: 01007 535 7441

To Infinity and Beyond: Age-appropriateness in play and leisure activities a leaflet produced by and available from Action for Leisure, c/o Warwickshire College, Moreton Morrell Centre, Moreton Morrell, Warwickshire CV35 9BL

Reviewed in this issue:

Choice Discovered – A Training Resource produced by the Foundation for Learning Disability
Tel: 020 7535 7441

Approaches to Teaching and Learning (Including Pupils with Learning Difficulties) by Ron Babbage, Richard Byers and Helen Redding in associationwith St. John's School, Kempston, published by David Fulton (1999)

Transition and Change in the Lives of People with Intellectual Disabilities edited by David May published by Jessica Kingsley Publications (2001)

RESOURCES

Music Factory - a program about listening to sounds and building your own music from pre-defined sound clips produced by Widgit Software Ltd. 29 Queens Street, Cubbington, Leamington Spa, CV32 7NA or visit www.widgit.com
Make your own great sounding music, music with different access methods turning Can't into Can.

COURSES AND CONFERENCES

2001
MARCH

21st Delivering housing choices for people with learning disabilitie

This seminar will be of interest to anyone involved in enabling people to move into a home of their choice. Topics covered wil be: Tenancy Issues, Shared Ownership and People with Learning Disabilities.

Organised by: British Institute of Learning Disability
Venue: Newcastle
Further details: Liz Howells
BILD, Wolverhampton Road
Kidderminster, Worcs DY10 3PP

22nd A repeat of the above Seminar
Venue: Manchester

30th Action for Leisure Resource Centre Open Day

Small multisensory room; items to purchase; wide selection of toys, games and equipment; database of information; reference library of books, videos, journals and publications. College farm animals and garden centre.

Venue: Action for Leisure
Warwickshire College, Moreton Morrell
Further details: Tel: 01926 650195

APRIL

5th Design and Technology for Children with Severe and Profound Learning Difficulties

The course will illustrate available materials that support the development of practice in school and will consider some issues surrounding classroom organisation and teaching approaches.

Organised by: Sunfield Professional Development Centre
Venue: Sunfield School, Clent
Further details: Jackie Wadlow
Tel: 01562 883183
e-mail: Sunfield@sunfield.worcs. sch.uk

7th "Beat That!" Have Fun Making Music

Workshop for all those working with children and young people with profound and multiple learning difficulties. It includes: drumming using resonance boards, African djembe drums and percussion; chanting; creating and using silence; singing to enhance communication and listening; creating; and watching sessions in action on video.

Organised by: Beat That
Venue: Acton, London
Further details: Hilary or Bobbie
Tel: 01865 772213 Tel: o1865 351765

11th Action for Leisure Resource Centre Open Day

Small multisensory room; items to purchase; wide selection of toys, games and equipment; database of information; reference library of books, videos, journals and publications. College farm animals and garden centre.

Venue: Action for Leisure
Warwickshire College, Moreton Morrell
Further details: Tel: 01926 650195

27th to 29th Sherborne Association Course - Level 3

This 3 day residential course is for advanced practitioners and aims to extend participants' skill-base through a deepening awareness of SDM theory, philosophy, psychological aspects and application in various fields, e.g the arts and therapy

Organised by: Sherborne Association
Venue: Heathermount
Further details: George or Cyndi Hill
Tel: 0117 937 3647

30th Action for Leisure Resource Centre Open Day

Small multisensory room; items to purchase; wide selection of toys, games and equipment; database of information; reference library of books, videos, journals and publications. College farm animals and garden centre.

Venue: Action for Leisure, Warwickshire College, Moreton Morrell
Further details: Tel: 01926 650195

MAY

15th to 17th NAIDEX & Medtrade Exhibitions

Seminars, products, performances

Organised by: Touchstone
Venue: NEC Birmingham
Further details: Touchstone
Tel: 0208 332 0044
www.naidex.co.uk
Free Tickets: 0870 429 4428

19th "Beat That!" Have Fun Making Music

Workshop for all those working with children and young people with profound and multiple learning difficulties. It includes: drumming using resonance boards, African djembe drums and percussion; chanting; creating and using silence; singing to enhance communication and listening; creating and watching sessions in action on video.

Organised by: Beat That
Venue: Mabel Pritchard School, Oxford
Further details: Hilary Bobbie
Tel: 01865 772213 Tel: o1865 351765

JUNE

21st Feeling our Way: Using Touch with Learners with Multiple Disabilities

This is the third in the series of National Conferences which focus on creating optimal learning environments for students with multiple disabilities. This day will draw on the latest research and consider the role of Touch in promoting learning.

Organised by: University of Birmingham
Keynote Speakers: Dr. Stuart Aitken
Dr. Mike McLinden
Venue: University of Birmingham
Further details: Noreen Stacey
0121 414 3294
e-mail: N.M.Stacey@bham.ac.uk

13th and Cultural Issues in Sexuality Work with People with Learning Disabilities

The aim of the course will be to explore different cultural attitudes towards sex education and people with learning disabilities within services, as well as the practical implications of carrying out sexuality work with service users from a range of cultural backgrounds.

Organised by: Consent
Led by: Seema Malhotra
Venued: Harperbury, Herts
Further details: Consent
Tel: 01923 670793

14th Autism: Challenging Issues, Continuing Ignorance

Nationally recognised speakers in the field will explore a range of themes including; genetics and environmental factors; diet and autism; Muchhausens Syndrome by Proxy; Educating the Health Professionals; Managing Challenging Behaviour. The conference concludes with a panel discussion.

Organised by: Mole Conferences
Venue: Regents College, London
Further details: Mole Conferences
Tel: 01273 242 634
e-mail: enquiries@mole-conferences.com
www.mole-conferences.com

27th to 28th Circles Network - CREDO Conference
Organised by: Circle Network
Venue: Posthouse Hotel, Birmingham
Further details: Circles Network
0117 939 3917
e-mail: frances@circlesnetwork.org.uk

JULY

5th Shake It 'n' Make It
A day of workshops, hands on (+ feet on) sensory experiences which you can transfer to your own early years setting. Join in sensory circle time, gather Rag Bag ideas, to make, to buy and to do.
Organised by: Bristol City Council
Venue Woodside Family Centre, Kingswood, Bristol
Further details: Margaret Nutt
Tel: 0117 947 5262

6th Sherborne Association Course - Level 2
Follow-up Course to allow participants to extend and reinforce knowledge gained during and subsequent to Level 1
Organised by: Sherborne Association
Venue: Heathermount
Further details: George or Cyndi Hill
Tel: 017 937 3647

SEPTEMBER

10th to 12th BILD 2001 International Conference
Equalising Opportunities for People with Learning Disabilities.
Themes will include: obstacles to inclusion; lifelong learning; education; equal opportunities for vulnerable adults; specialised v. mainstream services; civil rights/human rights; needs-led services; what is best practice; challenging behaviour.
Organised by: BILD
Venue: Cork, Ireland
Further details: Liz Howells
BILD, Wolverhampton Road,
Kidderminster, Worcs DY10 3PP

TATE BRITAIN workshops

Make your Mark - regular workshops which can be adapted to the needs of a wide range of groups. The emphasis is on using practical acativities to explore works on display such as markmaking, drawing with wire or simple movement tasks. There are a number of themes from which to choose: Space, Relationships, Feelings, Symbols or Construction.
Further information from Tate Box Office, Tel: 0207 887 8888

IN-HOUSE WORKSHOPS

Exploring the multisensory environment
Music for PMLD Children
Introducing Aromatherapy
Communication
Workshops carried out at your own premises, tailored to your exact needs.
Concept Training Ltd. 15 Beach Street, Morecambe LA4 6BT
Tel: 01524 832828

University of Manchester
SHORT COURSE PROGRAMME

Adults with PIMD; Mental health and illness

Because of their lifestyles, people with profound intellectual disabilities are often at increased risk of developing mental illnesses

What is mental illness?
Are you concerned about the mental health of your service users?
Are you confident that you could identify whether a client was beginning to experience a mental illness?
Would you know where to get assistance?

A one day course presented by Dr. S. Rowe, Dr. N. Chaudhry and Community Nurses from the Royal Bolton Hospital. They will look at key issues to do with mental health and illness among adults who experience profound levels of intellectual and multiple disability [PIMD]. Using case studies and interactive teaching methods, this team will outline the processes of checking the signs of mental and physical health with adults including older people

This full day course is aimed at those who care for or work with adults who experience PIMD and other sensory or physical disabilities, including Day Centre or Residential Workers, Occupational Therapists, Speech and Language Therapists, School Nurses, Learning Disability Nurses, Support Workers, Care Managers, Social Workers, KS4+Teachers, and Psychologists.

It will be held in The Jubilee Room,
University of Manchester, Oxford Road,
THURSDAY JUNE 28
£70:00 (includes coffee at breaktimes but does not include lunch)

TICKETS: Phone the JTI Office 0161 275 3337 / 0161 275 3342

LONGER COURSES (with accreditation)

Interdisciplinary work with People with Profound and Multiple Learning Disabilities

A one year distance education course for practitioners and carers of children and adults with profound and multiple learning disabilities. The main focus is upon lifelong learning, communication and effective interdisciplinary collaboration.
Offered at four levels: Post experience certificate (level 1), Advanced Certificate (level 3), Post graduate diploma and Masters (level M)
University of Birmingham School of Education in conjunction with BILD
Further details: Sandra Cumberworth, tel: 0121 414 3466

M.Sc/PG Diploma in Learning Disability Studies

1 year full-time or 2 year part-time course.
This course meets the training needs of a variety of professionals involved in delivering services to children or adults with a learning disability, including registered nurses, social workers, doctors, occupational therapists, physiotherapists, speech and language therapists, officers in statutory, voluntary or private establishments, FE tutors, staff of SECs. It provides the opportunity to participate in and contribute to inter-disciplinary learning in a collaborative setting.
Further details: Stuart Cumella or Helen Bradley Tel: 0121 627 2853

Profound Learning Disability and Multi Sensory Impairments

Two year distance learning course combined with workshops.
For people who are involved with children and adults who have complex learning needs and sensory impairments.
Offered at three levels: Certificate, Advanced Diploma and Masters.*
University of Manchester Faculty of Education in conjunction with Royal Schools for the Deaf, Manchester.
Further details: Tel: 0161 610 0149
e-mail: jtioffice@rsd.manchester.btinternet.com

PMLD-Link

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Baldoyle
Dublin 13
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